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ABSTRACT

This site visit report describes the development and activities of the New Hampshire Family Support Network for families of people with developmental disabilities, and is based on a review of documents, interviews with key people, and participant observation. It begins with a brief history of family activism in New Hampshire, noting the early high level of cooperation between families and state and local officials. Activities of the Task Force on Family Support, established in 1987, focused on establishing principles of inclusiveness, studying what was needed and what was possible, developing creative proposals, and organizing for change. The Task Force's recommendations resulted in passage of two legislative bills, one establishing the statewide family support network and the other providing interim services for people on waiting lists of area agencies. Implementation has involved development of regional family support plans, appointment of coordinators, and establishment of local family support councils. Issues currently facing the network include incorporating a new concept of family constituency, cost cutting and community support, more permanency planning across agencies, broadening the mandate to include families of people with mental health needs, relationships between councils and area agencies, and self-determination by people with disabilities. Implications for other states are drawn. An appendix briefly describes the report's methodology. (DB)

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"LIKE AN ANGEL THAT CAME TO HELP US": THE ORIGINS AND WORKINGS OF NEW HAMPSHIRE'S FAMILY SUPPORT NETWORK

Center on Human Policy

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"LIKE AN ANGEL THAT CAME TO HELP US": THE ORIGINS AND WORKINGS OF NEW HAMPSHIRE'S FAMILY SUPPORT NETWORK

"Like An Angel that Came to Help Us": The Origins and Workings of New Hampshire's Family Support Network

by Bonnie Shoultz

January, 1993

This report is based on an October, 1991 site visit. It does not represent an evaluation of the Family Support Network, nor does it address issues that have arisen since then. The preparation of this report was supported by the U.S. Department of Education and Rehabilitation Services, National Institute on Disability and Rehabilitation Research (NIDRR), under Cooperative Agreement H133B00003-90 awarded to the Center on Human Policy, School of Education, Syracuse University. The opinions expressed herein are solely those of the author and do not necessarily reflect the position of the U.S. Department of Education; therefore, no official endorsement should be inferred.

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"Like An Angel that Came to Help Us": The Origins and Workings of New Hampshire's Family Support Network

by Bonnie Shoultz

Manchester, New Hampshire is the state's largest city, and has common urban problems such as poverty and unemployment as well as the advantages and excitements of a city. There, a young father and his two year old son live in a comfortably furnished two bedroom apartment. Their home also contains medical equipment, such as a respirator and a gastrostomy tube feeding machine. The child's life depends on caring and well-trained people, including his father and several nurses who are there 16 hours a day, as well as on modern technology. Unable to cope with her baby's overwhelming medical needs, the young mother left the family before the child's first birthday, but the father has always been strongly committed to keeping his son at home. The Manchester Family Support Council and staff members have supported the family with advice, home visits, help with insurance misunderstandings and denials, advocacy in regard to electric bills, arranging for counseling, respite care, and many other types of support over the past two years. The father describes the Family Support Council as follows:

> ...[they were] like an angel that we were looking for to come down and help us out. It was just, nobody had any answers for us, and we didn't know about

them at the time that we got involved in it [having a child with so many medical needs].[1]

For this family, Family Support first came in when both mother and father were struggling to care for their five month old baby with serious medical complications. It has supported them ever since.

In another Manchester neighborhood, a family of five, including the parents, two adopted children, and one young foster son, three years old, have recently been told by a doctor that the foster child should be placed in a private children's institution in another city. He is so active and unpredictable that someone must pay direct attention to him all day and much of the night. The Family Support Program's staff person and his foster mother brainstorm about services and resources to keep him with the family. The foster mother says:

> Luckily he is in a system [the Department of Health and Human Services, which oversees children in foster care] where someone is looking out for his medical needs... and then the school system's picking up, you know, educational needs and therapy needs, and we're already hooked up with our primary care pediatrician and the specialist, and then to help me coordinate all of that, we have the Family Support person, who knows exactly what's available, all the resources. And they [Family Support] know him...

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[1]Many people are quoted, some extensively, in this report. Their words were transcribed, verbatim, from tape recorded conversations, and were left as spoken for this report. Spoken language is not like written language. When it is transcribed, it seems ungrammatical at times and disconnected. This is normal and natural, and people generally grasp each others' meaning in their conversations. Unless absolutely needed to clarify the meaning of something, changes were not made in what people said as they spoke, often with great animation or concentration, about issues that were important to them.

Even with these services, the doctor recommends that he be placed in the children's institution, but his foster mother says, "I'd hate to see that happen. I don't think he would ever be adopted from there. We've invested so much in him, we want to see a happy ending where he could be adopted." So together she and the family support worker develop new options for keeping him at home with services designed or adapted for their family. This family's services are funded through several programs, with the only Family Support Council service being the help from the staff person.

Finally, in a much smaller town in another New Hampshire region, a teenager with autism lives with his mother. The Family Support Council helps this family by arranging regular after-school assistance while the mother works, with respite care for other times, and by paying for other needs that cannot be met elsewhere. Until the Family Support Council was formed, they struggled along with the help of friends and neighbors. They still get help from their friends and neighbors, but the family is no longer dependent only on what they can give. Now they have some regular, paid-for services to fill the gaps.

Report Overview

This report reviews the history of family activism in New Hampshire, the activities of the legislative Task Force on Family Support, and the establishment of a Family Support Network consisting of a Family Support Council in each of New Hampshire's twelve regions for serving people with developmental disabilities. This report also describes the workings of the Councils and the Network, raises issues for discussion, and concludes with lessons to be drawn and implications for other states.

It is based on document review, interviews with key players, and participant observation (see Appendix for methods used in the research).

Family Activism in New Hampshire--A Brief History

New Hampshire's family organizations have been unusually successful in their efforts to achieve lasting change for people with disabilities and their families. Their accomplishments were the result of a tremendous amount of work, including an unusual degree of collaboration with professionals and nonfamily advocates. In New Hampshire, as in many states, parents and other family members, working with advocates, were successful in organizing to file lawsuits, improve conditions, obtain new legislative mandates, develop community services, and advocate that new laws be implemented as intended. In 1978, parents of people living in the state institution filed the Laconia State School and Training Center Class Action Lawsuit, with the initial intention of improving conditions at the institution. As in other states where such lawsuits were filed, these parents were active in the New Hampshire Association for Retarded Citizens (ARC-NH). One named plaintiff's mother was the ARC-NH president. While there were bitter disagreements among parents about how and whether to proceed with the lawsuit, the ARC-NH decided to file as strong a suit as possible. Today, many of the parents who disagreed in those early days have resolved their differences and are friends. A number of those who opposed the lawsuit have become articulate spokespersons for community life for all people with disabilities.

At least part of the success of family activism in New Hampshire can be attributed to a group of responsive state officials who listened to and encouraged

families to voice their concerns. For example, after a 1980 court order mandated the establishment of community services and the movement of people out of Laconia State School and Training Center, New Hampshire's only public institution for people with mental retardation, the responsible state officials frequently consulted the plaintiffs' parents and informed them of every step taken to carry out the court order. In the early 1980s, family members and professionals advocated together for community services benefitting children with developmental disabilities and/or their families, such as Early Intervention Services (established 1980), public education (implementation of PL 94-142, passed in 1978), and respite care (in 1982, family members worked with the state to secure increased funding so that respite care could be offered statewide). Family members, especially parents, sat on the newly formed Boards of Directors of the Area Agencies, participated as appointed members of the Developmental Disabilities Planning Council, and became involved in many other parts of the growing and changing New Hampshire developmental disabilities service system. Disability-specific parents' organizations, such as the Association for Retarded Citizens, played active roles in advocating for services for their sons and daughters.

In the 1980s, state and university officials and families began to attend to the concerns of families, not just to the needs of people with disabilities. A cross-disability families' organization, Special Families United (SFU), formed during the mid 1980s, after a "hostel," organized and funded in 1983 by the Developmental Disabilities Council and the University of New Hampshire, brought parents together for the first time to talk about their own issues. The parents who attended that meeting asked to

meet again and were given the support they needed to hold several statewide parents' retreats. SFU resulted from that series of retreats, and its newspaper, The New Hampshire Challenge, became a vehicle for statewide communication among families, regardless of the disability of their family member.

Also during the 1980s, Parents' Information Center (PIC), a federally funded Parent Training and Information Center, came into being for the purpose of training and informing parents about their rights and responsibilities under PL 94-142. PIC has trained educational advocates all over the state, and is frequently accessed by other parent groups who want information on their rights in the public educational system..

Through these and many other activities, parents and other family members were developing confidence, strength, and "savvy," according to Kathy Mandeville, a mother who later co-chaired the legislative Task Force on Family Support. She explains the effects of parent involvement:

> ...the more parents were encouraged to participate, the more parents became savvy parents who could sit through a meeting for 2 hours, and could keep minutes, and could say "You didn't discuss this." So there was growing a group of parents who were really pretty sophisticated, and we're a small enough state that people could come to Concord, and the Division was willing to pay mileage, or come to parents.

Like many other parents interviewed for this study, she credits people at the Division of Mental Health and Developmental Services and other state agencies for their willingness to listen and respond:

> ...it's not been all one-sided, parents demanding. It's also been an openness and a value system within the state system ... [the Commissioner] and his shop saying, "I agree with you, how can we both work on this?" So it's been a partnership, and one that's been equal, in terms of both agreeing or disagreeing on things. But there's been an honest give and take, I feel, as a parent.

Thus, over the years, a momentum was developing. Parents and other family members were talking to each other and to state and local officials, developing ideas and leadership abilities, learning about what was being done elsewhere and becoming aware of where the services in New Hampshire fell short. At the same time, they were supported and validated in many ways and from many directions. Some of the major supporters were the Division of Mental Health and Developmental Services, the Developmental Disabilities Planning Council, and the University of New Hampshire's Institute on Disability.

The Task Force on Family Support

A major gap in services in many parts of the state, acknowledged by parents, providers, and officials at many levels by the mid-1980s, was the lack of concrete support to families living with a family member with a disability. At a time when people were leaving the state institution and entering community service systems, many parents felt that almost all the resources were being spent to serve people who had been in the institution. Families who had not institutionalized a family member felt as though their needs were left out of the planning. When they needed community services, their family members were placed on waiting lists. They could get respite

care, but many perceived the respite services as inflexible and unavailable, especially when there was a family crisis.

One exception to this pattern occurred in the Upper Valley, an area surrounding Hanover and Lebanon in the western part of the state. Here, a group of parents started the Upper Valley Support Group, which became a family support service over the years. They applied for grants, held frequent fundraisers, and used the money they raised to coordinate and pay for a variety of family support services. Some of their programs included respite care, educational advocacy, family networking, Parent to Parent matching, a Community Partners program that matches families with community services such as Big Brothers-Big Sisters, Saturday morning play group, recreation programs, family recreation events, and a pediatric respite training program where pediatric residents from Dartmouth Medical School provide respite for families as part of their training. The Upper Valley Support Group was an important model, showing people in other parts of the state that creative and flexible programs could be instituted to support families. One of the parent founders recalled the early days

> ...when we just met in somebody's kitchen. And had some ideas of some things that we would like to see happen. And we started writing some grants and we got a director and we got space and you know, we just kinda grew.

Before they had money to rent office space, the director answered the telephone from her house.

In most of the state, however, there was a growing awareness that the system was lacking in its ability to support families whose family member with a disability lived

at home. A former case worker, who later became a legislator, described the situation:

> the class action clients got first priority 'cause the heat was on, the court had acted...So in many ways we had a two tiered delivery system. It was not too just. And in many ways also this was not the desire of administrators...but that's the way that it was due to the litigation. And so in a way the families within the region that I was becoming familiar with were really...(they had) people with disabilities just as entitled but...it was almost like because they kept them at home they were being punished.

While some states (e.g., Michigan, Maryland, and Wisconsin) had passed legislation that was meant to create flexible family support programs, New Hampshire had very little. Only the Upper Valley Support Group had an array of family support programs, and even here there was not the capacity to meet the unusual needs of many families. The example of other states' success, along with the growing dissatisfaction of families with their inability to get services, culminated in a decision by state policymakers and family activists to do something about family support.

In 1987, a bill written during the previous year by the Division was introduced by freshman legislator Frank Tupper. The bill, signed into law on April 3, 1987 by Governor John Sununu, was "An Act establishing a Task Force to study support services for families with developmentally disabled children." There are many opinions about why this bill was introduced. One state administrator said it happened because "the Division purposefully set out to create a constituency called families" through the family

support effort, knowing that this constituency would build and that its interests might diverge from the older constituency that had formed around the area agencies. A legislator felt it happened because it was the right time to study the idea of supporting families, and the right thing to do. A parent said it happened because families were pushing for change:

> So the Division had, partly as a result of their own decision and partly as a result of our input, an open forum, inviting parents and giving them mileage...-(in) November of 1986. And we went, and we told them that it's gotta change. That if you really want to help us, respite care is what keeps us together. It keeps us from placing our kids out of home, or having Friday afternoon emergencies. Allows us to keep a marriage from breaking up, or at least minimizes all those things. And we gave them specifics about what needed to be changed about all that, and they listened!

Perhaps what a legislator said sums it up the best: "Sometimes things get started at many levels." A number of people--family members, state officials, providers, and at least one legislator--thought that family support services were needed in New Hampshire, and acted to set up a legislative task force to study the issue.

The legislation passed easily. There was no appropriation, and the concept was easy to support. New Hampshire's many legislative study committees have had fairly typical histories. A legislator states:

> what I...and other people within the political process were aware of, was that blue ribbon commissions and task forces are more or less a dime a dozen.

Every report is done, it's studied and most of the time it winds up in the archives or on somebody's shelves. Good: now we took care of the homeless, now let's move on to the next issue. What's that--sexual harassment? Let's have a task force, and we'll study what we've done. And we knew that...

While that history may have allowed for the easy passage of the Task Force legislation, it spurred on the people who planned to activate the Task Force. From the beginning, they committed themselves to making their study mean something.

The legislation specified the membership of the Task Force. Traditionally, a legislative task force or study committee was headed by a legislator. Other members mandated in the bill included the director of the Division of Mental Health and Developmental Services, a representative from the Developmental Disabilities Council, a representative from a community based area agency, the director of the Bureau for Special Education Services, and two "parents of developmentally impaired children." The Task Force was mandated to begin meeting no later than June 30, 1987, to end within six months, and to assign at least one staff member from the Division of Mental Health and Developmental Services "to aid the task force in administering its duties."

The Task Force Beginnings

In some ways, the story of the Task Force is more exciting than the story of the implementation of the resulting family support legislation. After the passage of the Task Force bill, Kathy Mandeville, a mother from Bedford, received a letter from Governor Sununu asking her to serve as one of the two parent members of the Task

Force. She became a co-chairperson of the Task Force, along with Representative Frank Tupper. She remembered:

> Went up to the first meeting, my two thoughts were, we had to identify the beliefs that we all had in common, and that I had plenty of things to occupy my time, and I didn't need something else that was going to be just an exercise. The other parent happened to be the president of SFU...And all of the heads [of appointed agencies] really did come, they didn't send their secretaries or assistants to take notes.

The group decided that a parent should co-chair the Task Force, but both of the parents were very busy. Kathy Mandeville had fewer commitments than the other parent, so she was asked to be the chair.

> I said I would think about it, came back two weeks later, and said that I would undertake it only if... I would assure them that I would create a structure under which we would get things done. That I was totally serious, that this was not going to be futile. That if people weren't equally serious, that I wouldn't participate or that they shouldn't participate. That we would begin on time, we would meet every two weeks, we would have two hour meetings, and we would decide when things would end. And that that was what they were buying if they bought me.

Frank Tupper, legislative co-chair of the Task Force, analyzes these early decisions as crucial:

Kathy Mandeville was the person who wound up agreeing to chair the Task Force and that was very significant, that was very empowering and very, very important...It was...common sense. Put the people that are going to steer it in the driver's seat, let them run it. Let them decide where it is we're going to go and let the other members from the Governor's Commission and so forth be a support to the families. So let the families lead, let the families take their Task Force over and go with it. And Mandeville did a superb job. (She) was a parent, had credibility with the parents, was articulate, was an excellent planner. We sort of were Mutt and Jeff, she was pretty good on keeping the thing rolling and I was pretty good on philosophizing.

With this beginning, the Task Force set to work. Early on, someone brought a banner with the motto, "When all is said and done, let us ensure that more is done than said." This banner was unfurled at each meeting and public forum. One member said:

> And we took that real seriously, when all is said and done, when this Task Force is completed let us as a Task Force ensure that more's gonna be done than what we've said.

This motto was used to end the Task Force report summary that was submitted to the legislature nearly two years after the Task Force bill was passed.

The Task Force was supported by Division staff members Ceil Connor and Al Robichaud, who collected information, kept meeting minutes, and worked on the final report that was submitted to the legislature and to the public. The members began by

drawing up a chart that set out all they needed to do to develop that final report. This chart included the major activities and plotted out when each should be accomplished.

Key Task Force Activities: Include, Study, Create, Organize

The Task Force became a strategic force for change on many different levels. By the end of its 16-month existence, many transformations had taken place. The Task Force and its constituent bodies--family members and their organizations, the Division and other state developmental disabilities offices, the area agencies, and much of the legislature--had reached a consensus about what must be done, and that agreement was documented in the Task Force Report and summary. Family members all over the state had organized and were poised to get legislation passed, had learned how to be effective advocates, and had many allies within state government. These transformations occurred because the Task Force process encompassed four critical components: inclusiveness, study, creative thinking, and organizing.

Inclusiveness

From the beginning, the Task Force declared that its meetings were open to anyone who wanted to attend and participate. People from other state agencies, including the Division of Human Services, the Bureau of Special Medical Services, and the Division of Vocational Rehabilitation, were invited to attend and contributed in major ways to the Task Force. People from the Parents' Information Center and the Upper Valley Support Group attended regularly, along with the parents from Special Families United. Thus, the Task Force meetings became a place where people with

an interest could speak their thoughts and work together, and where the major players in the state were included in the decision-making.

Another form of inclusiveness had to do with definitions. The legislation had used the term, "families with children who are developmentally impaired or multiply handicapped," which the Task Force interpreted as applying to families living with a family member of any age who had a developmental disability. The inclusion of families of adults with developmental disabilities recognized their needs and signaled their concern about all families. Inclusiveness continues to be an issue today. A current debate over whether family support services should include families of people with other disabilities is pushing families and state officials to deal with the many implications of that concept.

Studying--What was Needed and What was Possible

Another early Task Force decision was that they must learn what New Hampshire's families need and want, and what was being thought and done elsewhere about family support. To study other states' family support programs and ideas, the Task Force asked the Division staff members to gather information from research centers like the Center on Human Policy and Human Services Research Institute, other states' developmental disabilities programs, and national disability advocacy organizations. Before and during the Task Force's months of operation, the Division was sponsoring conferences on family support that brought in nationally known speakers to address these issues. All of this information was compiled for Task Force review.

The other area of study was to examine, within the state, the current lives, needs, and wants of families whose members had disabilities. To do this, the Task Force organized numerous regional public forums where families could testify and listen to each other, accepted written testimony (and oral testimony on audiotape) from anyone wishing to write instead of speak, and interviewed other families. Additionally, the Institute on Disability prepared a questionnaire, surveyed families, and compiled the results for Task Force and other public use. Early on, two things became apparent: respite care services, while appreciated, were not enough; and families needed more than just services that money could buy. However, the Task Force did not release preliminary findings from their study of family needs. Instead, the public forums and other fact-finding activities became part of the larger process of deepening grass roots commitment to the idea of change. Legislative committees or commissional panels rarely if ever come to rural (northern) New Hampshire for face-to-face dialogué with citizens. Families attending the forums, especially those held north of the Franconia Notch, were impressed that the legislature wanted to know what they thought, and the families then became interested and wanted to participate in the outcome.

Later, when the Task Force had almost completed its work, drafts of the recommendations were widely disseminated for comment. Kathy Mandeville recounted:

> ...we sent out two drafts of recommendations to all families in the state and said, "What do you think of this?" As well as service providers. And asked "Do

you think this is good? Do you think this is realistic?" Two things--it got their input, but the other thing was that everything we did raised expectations. So they were invested.

Thus, the information-gathering activities became opportunities for input and investment in the process and the outcome by families and service providers, a pairing of study and action that fed into the political organizing that followed.

The Creative Process

While they did consider the different ways family support is organized and provided in other states, the Task Force developed ideas that took New Hampshire's political, economical, cultural, and social environment into consideration. They discussed what they knew and believed about the people in their state (for example, people value families, but they also value frugality). Perhaps the most creative idea was the recommendation that there be legislation to establish a comprehensive family support network, not just services, in New Hampshire. The network's structure would include statewide and regional family support councils made up of family members of people with developmental disabilities; these councils would be represented by a state coordinator and 12 regional coordinators, and would have funds specifically designated for flexible use by the councils for the benefit of families.

The Task Force made 23 recommendations in all, only two of which required legislative action. The other recommendations related to needed action that could be taken by public and private bodies, including state agencies such as the Department of Education, state-funded human service programs such as area agencies and

private providers, the New Hampshire Bar Association and Medical and Dental Societies, and by individual families, who were urged to expand their involvement in all areas. They felt strongly that no priority should be given to any recommendation over another, and therefore did not number their recommendations in the report.

Organizing for Change

While the Task Force worked, a number of other parties also prepared families to organize for legislative and executive action. The New Hampshire Challenge, the widely circulated new newspaper of Special Families United, became a vehicle to inform people of the Task Force's progress. The Institute on Disability at the University of New Hampshire held the first Family Leadership Series in June, November, and December of 1988. Family Leadership Series, an annually held training series for selected family members, focuses on identifying needed changes and learning about how to achieve them. The 1988 series had two days on developing a vision of what could be, two days on community organizing, and two days on advocacy through the legislative process, in which family members learned how to organize to get legislation passed.

All over the state, people were talking to each other and preparing to push for passage of legislation for family support. The Task Force process was therefore an organizing mechanism as well as the fact-finding and recommending process the legislature was accustomed to in authorizing such studies.

The 1988 Legislative Session

During the 1988 legislative session, two bills were introduced and passed that

furthered the momentum. Chapter 50, submitted at the request of the Task Force, extended the Task Force work until December 1, 1988. Chapter 59 authorized the creation of two Family Support Pilot Programs, and gave the area agency based in Nashua $50,000 and the area agency in Portsmouth $25,000 to administer model family support projects. The bill also required evaluations of these programs for the legislature.

"For the love of our families, for the sake of us all"

The Task Force report, titled "For the love of our families, for the sake of us all: A Report on Support Services for Families with Members Who Have Developmental Disabilities," was formally submitted to the New Hampshire legislature and Governor John Sununu on December 1, 1988. The Report, a 65 page document that encompasses a description of the Task Force, the issues confronting families, a statement of values and family needs, the Task Force recommendations, and some concluding statements, was too long for widespread distribution. Therefore, they prepared an accompanying 3 page, 2 sided foldout pamphlet that summarized the report, had a distinctive look to it (with pictures, the motto, and easily read sections set off by shaded headings), and could be disseminated throughout the state.

The final product was innovative in a number of ways. First, it stated that families needed a network, not just services, and that the network needed to link families statewide. Second, it envisioned this network as an entity the legislature could mandate, thereby ensuring the legitimacy of families working together to plan services, advise staff members, and oversee the spending for services. It also identified many

areas in which problems existed for families, the solutions to which would not necessarily entail spending public funds, and recommended actions that would address these areas. Finally, the recommendations included individual actions that could and must be taken by family members. The Summary and the Report of the Task Force are attached as appendices to this report.

Waiting List Legislation

Other events affecting the family support legislation occurred around this time. During the first Family Leadership Series, the family members involved had decided also to push for legislation to fund services for people on waiting lists of the area agencies. People involved with passage of family support legislation met with those wanting services for people on the waiting list. The year was seen as a very lean year for the state, in which it might be difficult to pass even one piece of legislation requiring an appropriation. The discussion centered around whether they should collapse everything they wanted into one bill, defer either the family support or the waiting list request, or strive to have two bills passed. Kathy Mandeville remembered:

> ...there were a lot of mixed feelings, a lot of people felt it was bad budget wise, that either we shouldn't introduce the bills, that they would both get shot down, or that Waiting List, because it was direct money for services, which was a crying need at that time, needed to be put in with Family Support, or that [the two bills] would create factions of families, one for Waiting List and one for Family Support. And what we decided at the end of that meeting, and I was emphatic about it, was that I can support both pieces of legislation. Neither

one cancels the other out. Both are totally legitimate, both flow from one another, and both will save money in the long run. And if the least it does is educate legislators, we will have created a lot. But what we have going for us now is all these families who know what's going on. And it's stupid just to shelve this thing. So both were introduced.

With the decision made to submit both bills, the families agreed to support both with equal vigor.

Passing the Legislation

After the Task Force submitted its report, a press release announced a Celebration in Concord. Held January 11, 1989, the celebration was attended by family members, providers, state agency staff members, and legislators. At the same time, family support legislation was being drafted by Dick Lepore, Division Director of Developmental Disabilities Services, a state senator and other people working at the Division. The legislation was based on the first set of Task Force recommendations and called for a network of family support councils and family support coordinators throughout the state. Senator Berry introduced Senate Bill 195, which requested $3 million for the biennium (two year period for which the legislature sets a budget) to establish family support services throughout the state, in the Senate Public Affairs Committee on January 23, 1989. The Waiting List bill, which was introduced in the Senate Public Institutions Committee on January 30, 1989, requested $5 million for the biennium. One participant recalled:

we knew we had a formidable task, because the state legislature in New Hampshire is the largest, a body second to Congress and I believe the British Parliament. Four hundred and twenty-five legislators needed to be spoken to. ...going into this we had a new governor. Governor Sununu had gone to Washington leaving what he had said was a surplus of 22 million dollars...as it turned out, just as we were entering our bill, within about a week or so after the bill...the new governor had made an announcement, after talking with his budget people, that it looked like instead of 22 million to the surplus, that the state had a 13 million dollar deficit. In the state of New Hampshire that was a lot of money...now we were beginning to see the bust was coming...it was as if "the bus is moving but you better not get on it this time."

In spite of this climate, everyone remained committed to passage of the legislation. Along with many others, including the parents trained through the Family Leadership Series, the Task Force members became advocates for passage of both pieces of legislation. Kathy Mandeville acted as spokesperson for the Task Force during the many hearings and meetings that were necessary during the legislative session. Frank Tupper, who had not been re-elected at the end of his first two-year term, videotaped these hearings and meetings. His silent videotaping presence made him, as a former legislator, "the conscience of the legislature," according to one of the participants.

By January 14, 1989 over two hundred family members and other bill supporters had received training on the legislative process, and had made personal

commitments to seeing the legislation through, to testifying, meeting with their local legislator, writing letters, and appearing in public. One trainer remembered:

> I can remember as we were training parents as to how approach the legislators, how to give testimony. We had a wonderful trainer that was brought out by the Institute on Disability as I recall...they helped provide some leadership training to parents who...voted once a year, but they didn't know their senator, they didn't know their representative. They never even thought they could meet the governor. And the interesting thing that you find out was parents or not, whether they had children with disabilities or not, that the political process was alien to most people. A lot of people didn't know you can talk to your representative...So there's some real basic civic lessons that had to go on as well. I think we believed, and rightly so, that the best stories were going to come from the families themselves.

The trained family members went back home, trained others, set up telephone trees, and invited their legislators into their homes to meet their families. Many became friendly with their legislators:

> I mean that's their senator...and some people knew him as Eddie, because I mean you know the guy's got a, he's got an oil station. Home oil, heating oil, that's his job when he's not in the senate. So a lot of people get heating oil, so some people know him as Eddie...So when you got in there, you say "Eddie, oops I'm sorry, am I suppose to say Senator Eddie? or..." Okay. He says, "Heck, I'm Eddie." Well, when somebody says "Call me Eddie," you do.

Then, after the Family Support bill was introduced, they began attending every committee hearing.

> And then we started the hearing process and one by one started knocking them down and they were voting yes. As I remember it went through eight separate hearings, eight separate executive sessions, and of all of those eight committees on both sides of the house and senate prior to getting to the governor, out of 425 legislators of the house and senate, there was one "no" vote. That was in the Senate...So we dubbed him Senator No and never let him forget it.

Throughout the process, the family advocates were there and very committed. At one critical juncture, they became aware that the Senate Finance Committee was considering funding the Waiting List bill with money taken from the Women, Infants and Children's (WIC) program. They were concerned about this possibility:

> And the parents were at their finest. We were allowed to be at the executive session. By this time friends were being made, and people like Gene Penzer's now the speaker, I mean the senate president...He was from Rochester, New Hampshire. Just kept the loving pressure on him...At 3:30, boom, in come the parents to the executive session. They just stand, and they [legislators] start talking "...how are we going to take it from WIC?" And parents...just start going (sighing) like this and then one of the Senators said "Is it all right with the chair? For I see that some of the parents are here, they seem to be disturbed by this. Let me ask them what's wrong," and the chair said "sure." So then when that

happens, when the executive session asks a person in the audience then you talk. [In committee meetings, no one who is not a member can speak or testify unless the committee chair requests it.] It's not like a...public hearing, so these parents came in and said, "If you're going to do anything, kill the bill. We don't want anything. If you're going to take it away from women and children who need milk and supplies and nursing and maternal care and so forth, we'll go at it another year if that's what you're going to do."...Pretty gutsy...But from in here (indicates heart). "We're not going to stand on somebody else's grave to get what we want." That impressed them. It was crazy but it was impressive.

The Family Support bill, which became Chapter 255, survived a threatened veto by Governor Gregg and was enacted into law on May 26, 1989, to take effect July 1, 1989. The appropriation was set at $500,000 per fiscal year. The Waiting List bill, which became Chapter 280, was enacted into law three days later, to take effect on July 1. The appropriation for this bill was set at $1.5 million (not from WIC) in FY '90 and $2 million in FY '91. On June 21, a huge party was held to thank the legislators, and Frank Tupper recorded the celebration on videotape. He later made a 19 minute videotape about the bill's history and passage.

The Act Establishing A Family Support Network: Chapter 255

The decision to have two bills was critical. First, it acknowledged that there was great need for both family support and services for people waiting in the community. Second, the bills went through the legislature through different routes. Having two bills made it clear that there were differences between the two concepts, and, most

critically, permitted family support services to be administered differently than the waiting list services. The separation allowed the concept of family support councils and a family support network to stay intact. If the two bills had been folded into each other, it is hard to see how this concept would have survived.

The passage of the waiting list act was seen as another victory for the families, but the money was allocated directly to the area agencies. The three-page family support act, on the other hand, laid out a number of principles for family support, recognized families as "the greatest resource available to individuals who are disabled," and created "a comprehensive statewide family support network" to support families, especially those living with family members with disabilities. Conceptually and in its implementation, it represents a different way of doing things in the state. It puts families into a new position, at least in regard to the services for families.

The Task Force members' belief that the values must be spelled out was incorporated into the legislation in the following principles:

(a) All children, regardless of disability, belong with families.

(b) Families must receive the support necessary to care for their children at home.

(c) Family support must focus on the entire family.

(d) Family support must be sensitive to the unique needs and strengths of individual families.

(e) Family support must build on existing social networks and natural sources of support.

(f) Families must have access to appropriate services to meet their needs.

(g) Family support is needed throughout the lifespan of the individual who is disabled.

(h) Family support must encourage the integration of people with disabilities into the community.

These principles are based on those developed by other organizations and states across the United States, such as the Statement in Support of Children and their Families promulgated by the Center on Human Policy in 1986. They were also derived from the findings of the Task Force, written into the legislation with an eye on New Hampshire and the values (for example, a "we take care of our own" value system, and a belief in families) held by its citizens. Many of the interviewees recalled how important the principles were in establishing the local programs, which used them as guideposts for their local decision-making regarding how the programs should be structured and operated.

The Act also stipulated that:

> The division shall establish a family support council in each area which shall consist of persons who have a developmentally disabled family member. The family support council shall provide advice to the area agency in the development of a family support plan for the area and shall monitor the services provided pursuant to the plan. A family support coordinator shall be available within each region to assist families in acquiring the supports and services outlined in the family support plan. The family support coordinator shall work

closely with the regional family support council to monitor the services provided to families.

The language of this section is both specific regarding the establishment of the regional councils and coordinators and ambiguous in regard to the respective powers of the councils and the area agencies. This ambiguity has permitted the development of a number of different ways of administering the family support plans.

The next section of the Act stipulates the Division's rule-making responsibilities. It directs the Director to adopt rules relative to further definition of services, eligibility requirements, manner of providing services, size of regional family support councils, and assignment of family support coordinators. In 1991, the Division was just beginning to develop rules and standards that would address these issues.

The final section of the Act appropriates $500,000 annually for the next two fiscal years (July 1, 1989-June 30, 1990 and the following fiscal year) to the Division of Mental Health and Developmental Services. The appropriation was down considerably from the original request for $1.5 million for each fiscal year, but it was a start. The Act says nothing about how the money should be divided.

Frank Tupper also noted that "to further protect the work we had accomplished, we made sure that the legislature had this bill enrolled so that the Family Support funding would be "line itemed" in the state's operating budget, and not just funded for one biennium."

Implementation

One of the Division's first acts was development of a rationale for dividing the money between regions. Each region's allocation is based on its percentage of the state's population, and the range is between $14,000 and $74,000, with the latter figure going to the most populous region. Family support councils, made up entirely of family members of children and adults with developmental disabilities, were formed in each of the regions. The Division asked the councils to work with the area agencies, which would be receiving the monies, to develop a family support plan for each region.

The Family Support Plans

The Division developed broad guidelines for how the plans should look, and reserved the right to disapprove a plan or send it back to be reworked. The plans were to specify what staff would be hired, the qualifications of the family support coordinator, whether extra money or resources would be added to the allocation and from where this would come, where the program would be housed, how much money would be set aside to purchase goods and services for families, and in what general categories money would be spent (indirect services, vouchers, medical assistance, emergencies, etc.). Plan developers were asked to use a "whatever it takes" philosophy and were given latitude in how the plan could look.

In some regions, the plan was developed relatively quickly, and the Division released the funds upon approval of the plan. In several regions, the area agency director and the council disagreed on issues such as where the program should be

housed, to whom the staff members should report, and who should have the authority to make spending decisions based on family requests. In some of these regions, a compromise was reached. A few councils, frustrated over their inability to come to agreement, asked the Division for concrete guidelines as to what they should do. The Division resisted this pressure, feeling that they needed to decide for themselves what would work best in their areas rather than adopting a model passed down from the state level. Finally, the last council did submit an approvable plan, and the Division released the last of the funds.

The Councils Today

A Division staff member gave the Division's perspective on how the councils operate statewide:

> And they began off great. Since that time some family support councils have become very involved in their regions and make all decisions as to the use of the funds. In other cases, they make recommendations and the coordinator basically...provides the care and the services as needed.

In some regions, the allocation was barely enough to hire a part time coordinator and, by housing that person at the area agency office, to have a few thousand dollars to spend on family requests. In others, the area agency contributed resources such as its respite care budget to the original allocation.

There are similarities in how the programs function. For example, every program provides information and referral, typically to any family, regardless of the type of disability. Every program has some cash to pay for family requests, as defined

by the families. They all adopt a flexible approach as to what can be purchased. The Division made suggestions about some matters, as an administrator explained:

> Most councils, at our request, did set up a ceiling on how much a single family would get until the coordinator had to go back and ask the council what to do. We wanted the coordinators not to be bogged down with getting permission to do everything, so we simply said 'you tell us what figure you feel comfortable with...For either a single request or an accumulation of requests from a family.'

Therefore, in each area the coordinators have the latitude to make decisions on expenditures per family up to a certain amount, and can simply report these decisions to the council at the monthly meetings. Beyond that amount, they get permission from the council. For example, in one region staff members can spend up to $300 on each family without getting permission. For amounts between $300 and $500, they can call the Executive Committee for permission. For amounts over that, they must wait for a Council meeting.

No area received enough money to meet the anticipated need, however. Partly as a result, coordinators and councils across the state have seen "going to the community" as part of their job from the beginning. That is, they have identified existing resources such as social services, benefit programs, civic organizations, and political organizations, and helped families to access them. The councils, discussing family requests, suggest ways of meeting needs through other channels, including their own relatives, friends, and connections, their places of employment and associations to which they belong, and the service people they know and trust. They

also rely on and develop the network of families, finding ways that families can help other families. For example, they may organize equipment loan programs so that their good used equipment can be loaned to other families. The treasurer of one council gave an example of how they work with the community:

> The Council bought a used washer and dryer for one father, and when the service man came to install them he found out the guy's microwave was broken, too. He gave him a new one, and said, 'Here, you take this one. You've got enough problems!' That father told us about it, and now we give all our business to that service man.

In another community, the Republican Women's Club, of which the coordinator is a member, put on a major fundraiser for the program. This same coordinator once asked a lumberyard to donate lumber for a ramp for a family and found a group of carpenters who would volunteer their time to put it up. The original estimate for the ramp had been over $1,200. During our research, we were told of many other examples of "going to the community."

Across the state, councils and coordinators make use of their network to share ideas about supporting families--about what family support might mean, about how to do it, and about who should oversee the programs. The bimonthly meetings of the family support coordinators and the quarterly meetings of the state advisory council, which is made up of representatives of the local councils, allow people to get acquainted and describe what they are doing. Sharing also occurs, usually by telephone, between meetings. In one region, for example, the council members felt

the area director was trying to control the council. Their meetings were held at the area agency office, and the director always attended and (council members felt) interfered. A representative called members of councils from other regions, who advised her to suggest meeting in another location, not inviting the area agency director. Councils that operate fairly autonomously, working with the coordinator and family support program staff in regard to family requests, feel strongly that family support means that families must be in charge, making the decisions as to what is done and how money is spent, and they voice that belief in many ways.

Issues and Challenges

While New Hampshire's network of family support councils and coordinators has many strengths, there are several issues that may challenge state officials, family members, and others involved in the program. This section will delineate some of these challenges.

Changing the Constituency

Earlier, a state official was quoted as saying that the Division had set out to create a new constituency called families. The concept embodied in that official's statement was expressed by a number of people in the interviews, and is apparently a common way of thinking in New Hampshire about how the system might change. Changing the constituency, however, can mean many things, depending on who is talking.

In dictionaries, "constituent" means either "component" or "elector, balloter, voter." A constituency would be a group of voters or a group of component parts

belonging to a larger whole. From the Division's perspective, "constituency" appears to combine the two meanings, as in "voters who can effectively advocate with the legislature for the changes and appropriations we need." A critical part of this meaning concerns who the constituency interacts with to define what is needed. The earlier constituency, from the Division's perspective, formed around the area agencies and worked with their administrators to define needs. On the other hand, there is evidence that Division officials see the family constituency as working closely with the Division, rather than through and with the area agencies. One Division administrator said, offhandedly, "We access the families through the councils." The interview data also suggests that the family leaders view themselves as in willing partnership with the Division, more so than with the area agencies.

Cost-Cutting: How Much Can the Community Contribute?

As described earlier, the family support councils have relatively small amounts of money and have worked creatively to access community resources. At this point, this is generally not viewed as a serious problem. One Division administrator said,

> I think the best thing that could have happened to our family support services was not to get all the money we asked for. We would have used it, and we wouldn't have been hungry enough to go and make the community aware on behalf of family support...there will always be a need for money in the future I'm sure, but this [has created] the necessity of getting to know our families better, and linking families up with other families and not making them dependent on

the system, but finding out more natural ways of just how do I get this need met. I think we're doing okay.

A treasurer from one of the councils told about one quarter in which they spent less money than budgeted even though the number of families served had grown. He saw this as a sign that they have made so many inroads with the local communities in their area that people's needs are now being met without spending council funds.

Thus, the family support network began with considerably less money than had been projected as needed statewide, and many of the councils developed their creativity and flexibility as a result. However, more money will be needed in the future, as more families become involved and as the community resources fluctuate in their ability to respond to economic and social forces and demands. Already, councils are discussing whether to set up waiting lists, and some councils have restructured at least once so as to use their scarce resources more efficiently. Many needs are still unmet. However, at the time of the visit there was no plan to increase the allocation to the program, and no clear way of estimating how much might be needed, how much "the community" can contribute to meet individual family needs, or whether there is a balance that can be achieved between program and "community" resources.

What is "the Community," Anyway?

A common view seems to be that "the community" is everything that is not operated through an area agency. Civic organizations, informal networks, and other service agencies for people with disabilities and their families are viewed as community resources, and all are accessed on behalf of families. Little if any distinction appears

to be made between these types of resources, nor is an evaluative stance taken regarding resources. Thus, getting someone on welfare or public assistance might be spoken of as "involving the community," as might helping a family to enroll in a disability-related service agency. Either of these might be seen as equivalent to working through a council member's corporation to cover someone's electric bill or interesting a civic organization in building a ramp or modifying a family's home. Councils and others interested in support for families and individuals should think through how they talk about the community. Some questions might include: What is the community? What is the relationship of service organizations, especially those that use public funds, to our definition of community? Is there a distinction between publicly funded services and the community? Can we, or should we, judge some practices to be "better" than others in involving or using the community on behalf of families? If so, what distinguishes those good practices? And finally, in what ways do and can families and people with disabilities contribute to the overall well-being of their communities, and how can we build on and enhance these contributions?

Need for a Permanency Planning Philosophy Across All Agencies Serving Children

Services for children in New Hampshire are delivered through a number of state agencies. Early intervention and family support services are the responsibility of the Division, but when a child is voluntarily or involuntarily placed out of the home, other agencies are responsible for the child and family, such as the Division of Children and Youth Services and the Department of Education. Some children served by these

departments do not live with families at all, living instead in residential institutions or other forms of congregate care. Ideally, a coordinated permanency planning philosophy and practice would imbue all efforts on behalf of children and families. Such a philosophy would declare that families be given "whatever it takes" in the way of family support and that if a child left the home, vigorous family reunification efforts would ensue immediately. It would also require that children who could no longer live with their own families be supported in living in an adoptive or (permanent) foster family (Center on Human Policy, 1986). However, children are still referred for congregate care, and there are barriers to adoption, including families' realization that the adult system may not be able to serve a child who reaches adulthood. New Hampshire has not yet developed a permanency planning philosophy that includes all agencies involved with children with developmental disabilities nor the mechanisms needed to put such a philosophy into place.

Broadening the Mandate

A key issue at the time of the interviews was whether the legislative mandate should be broadened to include families of people with mental health needs. While everyone interviewed expressed concern about this group of families, many of the parents felt that the councils have neither enough money nor the right expertise or experience to provide good supports to this group of families, and that trying to do so under present circumstances would dilute their efforts for families of people with developmental disabilities. Although many of the councils now provide information and referral to these families, they are reluctant to purchase or provide other services

without considerably more resources. At least one council, in the Upper Valley region, does provide additional services to these families, partly because this is an area of special concern to the coordinator. Discussion also occurs about whether and how to serve families of children with other disabilities.

The argument in favor of broadening the mandate has to do with the mission of the Division of Mental Health and Developmental Services, which administers both mental health and developmental disability services. No one argues that families of people in the mental health systems (or families of children with other disabilities) have no family support needs, and it would seem to be more efficient to try to meet their needs through the existing mechanism rather than to create a separate mechanism, possibly one that would replicate the current family support network.

Many laudatory attempts have been made to address the issue. For example, some of the parent leaders have worked with family organizations representing other disability groups, helping them to define their needs and create a vision for meeting their needs. The state and family leaders are to be commended for the concern expressed for other families who are not now served, and for their attempts to resolve the issue. Their empathy is reminiscent of the parents' strong stand on WIC with the legislature in 1989.

Keeping Councils Fresh

During the first year or two, the councils were made up of enthusiastic people who brought their ingenuity, creativity, and humanitarian concern to the monumental task of supporting families of people with developmental disabilities. Initially, many

problems had to be addressed, and council members had opportunities to put into practice ideas that had only been dreams during the Task Force process. At this point, many of the problems have been resolved and their solutions have been incorporated into routines followed by the program and/or the councils. Traditions have been established, roles determined, and experienced council member expertise has grown. Like other organizations that go through development and maturation phases, the councils could grow stale. They could become self-satisfied, closed, rigid, or self-serving, providing little opportunity for new ideas and new people to enter. One leader made this point:

> ...the more specific you get about your own structure, the more you become a structure unto yourself. And potentially become [just] another nonprofit board of an area agency. You just happen to be made up of parents who end up being so knowledgeable about all of the details that nobody new can walk in off the street because it seems like everybody else is so sophisticated. The intent of the councils was to keep them real folksy. Real "come on out of your kitchen running, swallow your dinner in the car, get there, hear about other families and reinforce the issues they're dealing with, and go home and live your life." And I don't know how to keep that.

The continuation of the Family Leadership Series will undoubtedly help in developing family members who can serve effectively and bring freshness to councils. However, this will remain a critical challenge for parents, council members, Division and other

state office leaders, and advocates, one that must be addressed and readdressed through the years to come.

Relationships Between Councils and Area Agencies

Relationships between family support councils and area agencies differ across the state. In some areas, the family support council and program seems like a program of the area agency. In others, the council appears to advise the area agency in how it spends family support funding. In still others, the council apparently views itself as operating the family support program. The law establishing the councils specified that the councils were to advise the area agency on the development of the family support plan, but said nothing about how the councils were to operate.

It is clear that at least some of the councils view themselves as in charge of the program, to the extent that they are willing to exclude the area director from their deliberations if there is conflict over control issues. Describing his role, a treasurer of one area's family support council revealed his perception of their council's power and control over the program:

> I do the books. I'm the treasurer, and I follow through to see if it's what I thought it should be. And I budget. The budget, the first year, what were we given, [names a figure]? The second year, I upped it. The state didn't give me any more, but what we were doing was good enough that the area agency gave us that extra money.

State officials are comfortable with the idea that different councils operate differently, and have different relationships with the area agency directors. It is unclear, however,

whether a mechanism exists to allow the plans now in force to be modified as local needs change, or as family support councils desire more or less control over the program. At the time of the interview, councils were in the second to third year of plan implementation, and had not come to a point where they felt a need to change their plans.

The Role of the Councils Vis-a-vis the Areas and the Division

The family support councils, and the programs they administer, have the potential for an autonomy that no other area programs possess. At the same time, the local councils are interwoven into the area agencies' operations. Their operating funds come to them through the area agency, and their staff members are usually housed within area agency facilities. Often, a part of their budgets come from area agency funds, which are given to supplement the funds from the family support allocation. In several areas, a family support team might include one or more people who are viewed as area agency staff members, and there are probably many more ways in which the councils and the programs they oversee are intertwined with the area agencies.

As mentioned before, the councils, along with all the families they serve, represent a new constituency for the Division, new because of the direct ties between them and the Division. They are a different constituency, with different roles and interests, than the past and present independent family organizations such as Special Families United and The Arc of New Hampshire. The latter organizations have had a direct advocacy role, and were able to maintain independence because they did not

receive funding through the Division. Special Families United dissolved after the family support legislation was passed, and the parent leaders say its dissolution was due to their own desire to spend their energies locally, with the newly forming councils.

Because of all these factors, the relationships between the Division, the area agencies, the councils, and the independent parents' groups should be examined by the parent leaders in the state. Are there dangers in being tied too closely to funded programs, even when those programs directly benefit families? If the opportunities presented by the family support network legislation and structure outweigh these dangers, exactly how do they? Are there now, or will there be, other needed changes in the developmental disabilities system, and if so, should advocacy for those changes come from the council structure? If the answer to that question is no, then from where should that advocacy come?

Future Challenges

Several other issues surfaced as potential challenges for the future. The councils were still too new to have dealt with some issues, but they are worth discussing now to avoid problems in the future.

When Advocates Become "Providers"

How much control councils have over their own operation is likely to continue to be an issue, but may be an issue that creates a healthy tension between the state, the area agencies, and the family leaders. Potentially, this is an issue that could help to keep the councils fresh. On the other hand, their having control over a specific program could compromise the leaders or drain their energies, diverting them from

needed advocacy efforts in other areas and in regard to the broader picture of what is needed for people with disabilities.

What Happens When Families Need More?

Experience in other states and with families we know tells us that there will be families who need much more than can be provided through the current structure. Some of these will be families who simply need more resources than the program and the community can generate. Some will be families who continue to "fall through the cracks," who are determined to be ineligible for some or all of the disability-related services but are appropriate for the family support programs. Some will be families whose primary caretaker just needs someone to talk to on a regular basis, someone who can provide emotional support and pay attention to the little things. Some will be families with unusual needs, such as nonEnglish-speaking families, or families where a parent has a major illness or other life problem. Finally, some will be families whose values or behaviors are significantly disparate (possibly because of cultural or class differences) from the council members', and where there are miscommunications and misunderstandings because of those dissimilarities.

It was impossible, in one visit, to identify families with these problems. When questions were asked about families like these, however, the people interviewed admitted that they struggle with how to meet their needs, and that they realize that there are sometimes cultural and values conflicts that become barriers between the programs and some families. They typically said that so far, they've been able to find something that works. In the long run, if the family support program and the

community cannot meet the needs of families presenting these problems, then it will have failed to fulfill its mandate in an important respect. At least some families will be unable to avoid placement of their disabled children outside of the home, and many others will struggle along, unsupported in any real fashion. New resources, including a much higher direct funding level than is now available, must be marshalled if the councils are to meet these needs along with those of the growing number of families now coming to them with requests.

Self-Determination by People with Disabilities

Inevitably, there are times when family members' goals do not coincide. However, the concept of family support makes a number of assumptions about families, assumptions which may discount or ignore the needs, goals, and preferences of the family member with disabilities. For example, an adult might prefer to live away from the family, regardless of how much support the family could get to stay together. A parent, as his or her child matures, should not necessarily be the family spokesperson when family needs and wishes are being determined. The role of the family support worker may need to be quite different with a family whose member with disabilities is older, but the current system does not necessarily encourage a role change for the worker.

The issues of how to support and enhance self-determination by children and adults with developmental disabilities, and of how self-determination relates to family support, are not well understood in New Hampshire or elsewhere. Several people interviewed translated the issue of whether the rights and wishes of the person with

the disability might conflict with the family's wishes or practices into a separate question, how a family support council or coordinator should deal with a situation where abuse or neglect is suspected or identified. While this is an important issue, there are many other times when a person's need for self-determination may conflict with family concerns.

Conclusion and Implications for Other States

New Hampshire's family support network, comprising the statewide and local councils and coordinators and their linkages to other families within the local communities, offers many lessons for family activists and policymakers elsewhere.

There is much to be learned from the New Hampshire experience with family support.

- **They developed a clear vision and principles**, by which they measured all their efforts and ideas. The Task Force's vision and principles led the parents to refuse to permit WIC funds to be used for family support, and the principles set down in the legislation, drawn from the initial vision, guided the Family Support Councils in setting up their programs. From beginning to end, the vision and principles pervaded all their efforts.
- **They built a constituency**. The legislation would not have passed if they had not realized the importance of using all their early efforts to involve people, giving people training on legislative effectiveness, and guiding them to develop their own Councils.

- **They took into account the political and social context** in New Hampshire as they developed their ideas, rather than adopting another state's program. This undoubtedly boosted their creativity and helped them to get the legislation passed and the Councils underway.
- **State administrators had a history of collaboration with parents**, encouraging their active involvement in and advocacy regarding policy issues. This history played its part in their success, as the trust and knowledge of each other that were displayed could only come through ongoing relationships.
- **Parents were in positions of leadership**, probably because of this history of collaboration. Both in the Task Force, and in their ideas for how the family support program should operate, parents were put in positions of leadership.
- **They didn't compromise** on important issues, such as whether to merge two separate concepts and whether to take money from other families' allocations. In spite of the fiscal constraints that made success less likely, they held fast.
- **They pursued their goal when the constituency was ready for it.** Although they were advised to wait, they knew they were ready and should not wait for a better fiscal climate. At the same time, they did not proceed before the constituency had been organized.

- **Inclusiveness was valued**. From the beginning, when they broadened the Task Force mandate to include families of adults, until the time of the site visit, when they were designing ways of meeting the needs of new groups of families, inclusiveness was explicitly discussed and embraced.
- **Their research was careful**. By the time the Task Force was ready to report, they knew well the needs in their own state and the approaches used in other states. Their research helped them to frame their ideas and then became an instrument of persuasion.
- **State flexibility allows for regional differences**. In New Hampshire, regional and local differences are assumed and accounted for. At the state level, flexibility is built in so that these differences can exist comfortably.
- **The community can be a rich resource**. Even though there are dangers in having low levels of funding, there can be benefits, if community resources are involved and developed. The Family Support Councils in New Hampshire have discovered countless new ways of mining (and replenishing) the community's resources on behalf of families.
- **They built a family network around what could have been just a new or expanded category of service**. From early on, they wanted a network, and there is good evidence that the parent leadership uses that

network to strengthen their local programs and to connect families with each other.

The family leaders and policymakers in New Hampshire are people with concern for others, creativity, and energy. Their successful organizing efforts in bringing about their vision of support for every family living with someone with a developmental disability can be studied by people elsewhere who desire the same, or who wish to develop other programs that affect families.

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Appendix--Methods

This report is based on document review, interviews with key players, and participant observation. The interviews and observations were with key people nominated to us as having involvement with New Hampshire's family support legislation, the family support councils, and the Family Leadership Training conducted by the Institute on Disability at the University of New Hampshire. Based on initial telephone contacts with a number of key people for the study, August 24 and October 14-16, 1991, were selected for site visits. Appointments were made with those people who could be available on those days. Documents related to their activities were obtained before the visits and were used to inform the interviews, which were taped. Additional interviews with families and state or regional employees were conducted by two other members of the research team.

The interviews and observations were conducted with people at various levels within the state, including state officials with indepth knowledge of the program, the former legislator who co-chaired the legislative Task Force set up to study family support needs, three parents who were very involved in the legislative activities that resulted in passage of the Family Support Network bill, eleven parents whose families receive services through the Family Support Councils, two Institute on Disability staff members involved in the Family Leadership Series that has trained parents in advocacy skills since 1988, and employees of the family support councils in three regions of the state. The interviews and observations resulted in about 400 pages of

field notes, which were coded and analyzed to identify major themes for the report. Additionally, telephone interviews of other informed individuals were conducted to obtain further information and to confirm impressions formed on the earlier visit.